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ABSTRACT

This book addresses the specific needs and concerns of fathers of children with special needs. It summarizes research regarding fathers of children with special health needs and disabilities. It offers a new paradigm of service delivery to enable professionals to encourage fathers' involvement in their children's care. Innovative service delivery strategies to assist fathers are suggested as are means of developing effective father support programs. Statements by fathers of children with special needs appear throughout the book and provide insights into their needs and feelings. A resource section for parents and professionals is included. Includes 42 references. (DB)

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FATHERS OF CHILDREN WITH SPECIAL NEEDS:

New Horizons

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James May
SEFAM Family Support Program
Merrywood School

ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH

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ACCH, founded in 1965, is devoted to improving the ways in which the health care community responds to the unique emotional and developmental needs of children. Through advocacy and education, ACCH, its local affiliates throughout the United States and Canada, and its more than 4,300 members are working to develop policies and practices that promote the health and well-being of children and their families in all health care settings, in the community, and at home.

For more information, contact:

ACCH
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

Fathers of Children With Special Needs:

New Horizons

James May
SEFAM Family Support Program
Merrywood School

Managing Editor:
Mary McGonigel

First Edition
1991

ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH
BETHESDA, MD

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DEDICATION

This monograph is dedicated to my dad, Edward, and the special fathers who have taught me so very much about patience, perseverance, and the power of love.

Table of Contents

Acknowledgments vii

Foreword ix

Preface xi

Introduction 1

Research 7

A New Paradigm for Professionals 15

Strategies for Effective Service Delivery 19

Support Programs for Fathers 27

A Vision for the Future 35

References 39

Resources for Parents and Professionals 43

Your Turn to Share 49

About the Author 51

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-- James May

FOREWORD

Photo: Phil Davis

Phil Davis with his daughters, Deidre and Erica

I am the father of two children with special needs. I have learned that the birth of one's child is an event that changes a man forever; he becomes a father! Nothing can change that fact. How fatherhood is embraced not only affects the man, but also the child he has fathered. The father-child relationship offers a man his greatest opportunity to experience the full range of human emotions, from despair to hope, sorrow to joy, anger to love, panic to control, and responsibility to freedom.

This document celebrates fatherhood and is a tribute to those fathers who have given so much to their children with special needs. The myth that fathers are not vital to or involved in the lives of their children and are not capable of being nurturers will not withstand a reading of the pages that follow. Be prepared to be touched as you learn more — much, much more — about fathers.

Phillip B. Davis

PREFACE

A few years back I helped organize a fathers' support program on the East Coast. It was there that I met a father who has remained forever etched in my mind. He was a smallish man, with somewhat fragile features. He was carrying his daughter crooked in his right elbow, like a football ready to be handed off for an end run. A diaper bag was casually slung over his left shoulder. It was difficult for him to make eye contact, and he was hunched over so that he looked smaller than he really was. His infant daughter appeared fragile as a porcelain doll. His eyes rarely left her.

The ten men attending the group had never met before. As we went around the circle introducing ourselves, this father quietly gave his name and his daughter's name, and he mentioned she had *cri-du-chat* (cat-cry syndrome) and trisomy 10, a rare combination. After the usual uneasiness men experience in talking about concerns men never find it easy to talk about, a more relaxed air settled over the room. Topics discussed were broad: educational bureaucracy; physicians who do not listen or who talk in "jargon"; and the difficulty of accepting a child's slowness in grasping everyday tasks.

Bent over in a manner that spoke of sadness and resignation, the man continued to cradle his daughter. Asked if he had some thoughts to contribute to the discussion, he replied quietly, "Cloudy days, I want to speak about my cloudy days. My child was not supposed to live more than 6 months, but she is now 18 months old, so I guess she wants to live more than the doctors thought. I love her more than anything in the world."

Haltingly, he continued, "My wife would like to have her institutionalized, but I will not allow that to happen. I went to a genetics counselor and had some tests done; both defects have been traced back to me. I would have given anything to have known that before she was born. I seem to have cloudy days, a kind of gloom that hangs over my head. I can't quit thinking about my daughter and the life she has. If I tell my feelings to

my wife, she can't handle them and she will again want me to have our child institutionalized. For 18 months these cloudy days have been a part of my life. I would like them to go away."

This man, and thousands of men like him, demand our attention. Professionals now have the chance to build new bridges, to dramatically influence how families are served, and to create new paradigms, free of old limitations and constrictions. Together, we need the courage to construct a new vision for the future, a vision that gives fathers of children with special needs recognition and understanding, and most importantly, substantive programs — not add-ons — that speak to the unique concerns of fathers. To do so gives a man an opportunity to come to terms with his personal losses, a place to gain needed information and resources, and the possibility of learning new skills in his journey to be the best father he can possibly be. In turn, the families of children with special needs can be born anew.

In *The Structure of Scientific Revolution,* Thomas Kuhn (1970) wrote about building new paradigms from within. Institutions and programs must make necessary transformations so as to include fathers as integral members of the service delivery team, rather than keep the status quo. Our mission as care providers is to open new doors for father involvement. Only then can we be truly family centered — in spirit *and* in outcome.

James E. May
Bellevue, Washington

INTRODUCTION

The pain is not gone, nor are the nightmares suppressed. What is seen on the outside is not a mirrored reflection of the inside. What is real is that I have grown up and recognized the limitations that I have and realized that I can survive. My daughter's ability to learn and my wife's tenacity to teach her show me that "can do" spirit, and I should be no less in my effort.

— Kenneth Braker

Photo: James May

Nelson Holmes with his son, Nelson, Jr.

Fathering is the "single most creative, complicated, fulfilling, frustrating, engrossing, enriching, depleting endeavor of a man's life" (Pruett, 1987, p. 282). It is an undertaking replete with immense challenges and boundless joys. The past 30 years have forever changed the ways men approach these demands. Once thought to have a limited role in the parenting process, primarily as providers, fathers are now considered vital — indeed essential — to family health and well-being. As fathers are now routinely in the birthing room during delivery, so too are they directly engaged in child caretaking tasks and responsibilities. Increasing numbers are choosing to stay at home while mothers pursue full-time employment.

Many fathers are also discovering that balancing full participation in work and in family is tantamount to "exploring uncharted territory, with all of the missteps and false starts that such ex-

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ploration requires" (Bell, 1986, pp. 141-142). Men are being confronted by inadequate role models, a lack of child-rearing information and education, and a set of values needing reevaluation and revision. As described by Sanger and Kelly (1987):

> Most of the deeper pleasures of parenting arise from its nurturing aspects. . . . The more parents find that they can do for a child, the more they want to do. Because of the different way they are socialized, women know this but men don't. They will have to be helped to discover it. (p. 198)

While fathering is an old game, it is indeed now being played with new rules.

Fathers of children with special health care needs and disabilities confront such challenges every day. They must reconcile their conflicting conceptions of their roles as fathers and find new beliefs and expectations that incorporate and encourage their children's full growth and development. In sum, they must redefine themselves as fathers. What is this experience like for a man? Why is it so demanding and often so difficult? What are the feelings associated with such drastic changes?

We must begin by placing fathers in the context of their families. When we talk about a family, the whole is greater than the sum of its parts. All family members are interdependent; what happens to one clearly affects the others. Like a mobile, family members are in balance with each other. Because of their inherent resilience, families can withstand a certain amount of buffeting and maintain themselves well. However, remove or severely alter a part of the mobile and it will collapse.

Before Jacob I considered myself a conservative, but even my politics changed after Jacob. I now find myself concerned with people, causes, and what is best for my son.

— Gary Sweet

Having a child with special needs places immense pressure on the family mobile. Communication is strained, finances are compromised, resources are often limited, and parental roles may become stratified. Family members often feel isolated, helpless, and neglected. Life will never be the same. One dad likened having a child with special needs to living with a strident rock-'n-roll sta-

tion blaring full blast, nonstop, 24 hours a day. According to Hudgens (1979), chronic illness and disabling conditions are:

> . . . powerful forces that often control the structure, the actions and reactions of family members. They can effect sweeping changes in family roles, realign subsystems within the family, and isolate family members from each other and from outside influences. (p. 68)

The extensive stresses evoked in a family with a child who has special needs can leave a father feeling depressed, weak, guilty, powerless — and very angry. The dreams a man brings to his child's life — lineage, ego fulfillment, athletic and vocational achievement — are threatened. All fathers today, even those quite uninvolved with their children, will feel the loss more profoundly than did men just two generations ago (Cummings, 1976). Helplessness and immense frustration may ensue. A father's self-esteem is at risk. Lamented one dad at a support meeting, "That I can't control the disability still leaves me confused; that I can't seem to do anything just drives me crazy."

The fact is, having Sarah makes us different. My family is closely watched by friends and neighbors. A trip to the store or a shopping mall makes us open game for stares and whispers. Life is not typical for any of us, and we are constantly reminded of the reasons why. My love for Sarah is a deep love. It has to be, because there remains a lot of hurt that must be put aside.

— Paul Egly

These feelings are exacerbated by a service delivery system that too often excludes and disregards men. "It's as if I don't exist when the doctors talk about our child," declared the father of a nine year old with cystic fibrosis. Because services are offered during the day when most men are employed, mothers — even though often employed themselves — generally become the resident "experts." A father's base of information regarding his child may be very limited.

Even parent support programs, while inviting involvement of couples, are primarily made up of mothers, and the few men who attend often feel uncomfortable and out of place. The workplace offers little encouragement, as many men find it awkward to share personal concerns and feelings with their peers. In the minds of many fathers, stories about a child with special needs

cannot compete with success stories told by other men around the lunch table.

Of considerable consequence are our "culturally defined ideas of manliness" (Dittes, 1984, p. 2). The old male models that are part of the dominant American culture — being self-sufficient, competitive, and in control; capable of handling all problems without asking for help — die slowly. A man often has been taught that "the economic security of his family is his most sacred, possibly only, legitimate domain" (Pruett, 1987, p. 18).

Men need encouragement to engage in their children's lives in responsible, caregiving ways. The positive results of such involvement are endless. The family mobile begins to rebalance itself, channels of communication are broadened, and new doors are opened for fathers to discover the irreplaceable value they have in the lives of their children. As described by Pruett (1987), "a father may embrace his children, but until he embraces his own unique, irreplaceable value to them as a parent, he does not have as much in his arms as he thinks" (p. 281).

> ***Because of the "men only" sessions at parent training, my male ego is not so fragile, but God help you if you step on it. I still have a tough time expressing my feelings, as the fear of being less of a man is still in the back of my mind.***
>
> ***— Billy Rogerson***

Fathers have interests and concerns quite different from those of mothers, typically as a function of their family roles. This monograph will focus on those concerns through a discussion of the following areas:

- a highlight of research regarding fathers of children with special health needs and disabilities;
- the advancement of a new paradigm of service delivery to enable professionals to encourage fathers' involvement in their children's care;
- means for assisting fathers through innovative service delivery strategies;
- a focus on developing effective father support programs;

- envisioning the future — a look ahead; and
- resources for fathers and their families.

This monograph has a variety of uses: as an introduction to the subject of fathers of children with special needs; as the foundation for further study and research regarding the topic; as a resource for professionals and families; and most significantly, as the impetus for new, innovative programs designed to include fathers as integral to family-centered service delivery.

Since I am the most assertive in our family, I try to get things done one way or the other. . . . I never take no for an answer; if one door is closed I'll knock on another door till someone will open it for me and give me what I want for Sabra.

— Hameed Quraishi

Photo: Gary Sweet

Mark Christianson with his daughter Brooke

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RESEARCH

Rebecca has taught my family much about unconditional love. She has opened our eyes to the world of persons with special needs and made our lives the better for that. She is teaching us patience and the serenity to accept those things which cannot be changed.

— William Sheretz

Photo: James May

Jim Lamb with his daughter Lisa

The past three decades have brought about increased involvement of fathers in their children's lives. Unfortunately, little substantive research has been completed regarding fathers of children with special needs, especially when compared to the body of work about mothers of children with special needs or about parents of normally developing children. Even fewer studies have concerned families of color and families who are not part of the dominant American culture. Programs designed specifically for fathers with children who have special needs have been practically nonexistent, despite increased recognition of the role men play in family functioning.

A father's ability to handle major changes positively can greatly enhance household well-being. Conversely, a man's inability to cope with the changes inherent in having a child with special needs negatively affects the family. Such stresses demand open

> *Our life style has changed — and positively — it's not for the worse. . . . I am glad she is with us. . . . I wish God had given us some money along with Sabra so that we could have bought a rambler and a van with a lift. Maybe we'll get lucky soon.*
>
> *— Hameed Quraishi*

channels of communication, shared child care responsibilities, and the development of strong family and community resources and supports.

When the normal pattern of family interaction is disrupted through the birth of a child with special needs, parental roles often become tightly defined. Gallagher (1981) found that mothers of children with moderate to severe disabilities almost always are the primary caretakers, with their lives being fully involved in such roles as food shopper, nurse, child transporter, clothing purchaser, and household caretaker. Fathers assert their key roles as provider, protector, and household equipment maintainer. Although these families choose traditional male/female roles, both mothers and fathers in the study felt that, ideally, most roles should be shared.

Men and women may adjust to their children's special needs at a different pace and in a dissimilar style. While a mother may be grieving, dad may be concerned about the financial constraints placed upon the family, a difference that can add stress to a marriage (Price-Bonham & Addison, 1978).

> *Fathers are almost expected to run away from the problems of raising a handicapped child. . . . I feel that much of this comes from the male child raised in the "macho" image. He is told he shouldn't cry or have other feelings and that women are destined to handle certain situations. Fathers need to be reached as soon as possible to be assured that they can let go of their emotions without guilt and that they are needed in the family and can provide positive assistance.*
>
> *— Kenneth Braker*

All families with children who have chronic illnesses or disabilities experience pain and grief. Fathers hurt, and hurt deeply, yet they do not always show it publicly. They often keep the hurt stuffed inside, fearful they will lose control or will be seen as weak or ineffectual: "I must be strong for my family's sake, be the glue that holds us together."

This outward confidence may prompt others to believe a father is

"doing just fine," not realizing that his hopes, ideals, and dreams for his child may be shattered. A man's self-image, the desire for his family name to be carried on, the vocational hopes he brings to a son or daughter, will be seriously jeopardized. "Will my child ever be self-supporting? Will he be able to live independently and earn a living?" Such questions are of fundamental importance to many fathers (Hersh, 1970; Love, 1973; Meyer, Vadasy, & Fewell, 1982).

Not all fathers of children with special needs feel added stress because of their children's disabilities (Gallagher, Cross, & Scharfman, 1981). Several researchers have found that behaviors of fathers whose children have special needs in many ways resemble those of other fathers (Mitchell, 1979; Shanon, 1978; Widerstrom & Dudley-Marling, 1986).

Studies also indicate that a father's adjustment will be more difficult if the child with special needs is a son (Farber, Jenne, & Toigo, 1960; Tallman, 1965). As Frey, Greenberg, and Fewell (1989) state:

> Fathers may have more difficulty adjusting their expectations for their sons. Also, the traditional role of fathers, particularly with sons, is one that emphasizes joint recreation over caregiving. With more severe impairment, opportunities to engage in this aspect of fathers may be limited. (p. 247)

Fathers generally are more accepting of a girl with developmental disabilities than of a boy with such disabilities (Grossman, 1972).

A key factor in the acceptance and bonding between fathers and their children is the physical role that fathers traditionally play; many fathers glory in roughhousing with their children and taking them on outings. Both roles may be jeopardized (Gallagher, et al., 1981). Dads with children who have disabilities often need help learning to read their children's communication cues. The father of a four year old son with cerebral palsy remarked, "I just assumed my kid didn't love me; we never made eye contact. He didn't smile much, and he always cried when I threw him up in the air." Learning appropriateness in father-child interactions, acquiring sophistication in feeding and using

> *I have divided my life into two phases, before Jacob and after Jacob. Nothing is the same, but most changes have been positive. My wife and I don't have choices anymore; our lives revolve around Jacob. I have changed jobs just to get the "right" medical insurance plan. We have moved twice so that we could get into the "right" school district.*
>
> *— Gary Sweet*

adaptive devices, and gaining skills for family and child advocacy are essential.

A father's self-esteem may be at risk when he has a child with special needs (Farber, 1962; Ryckman, 1965; Tallman, 1965). Researchers have found fathers of children who are developmentally disabled or chronically ill to be depressed; many felt themselves to be "inferior" fathers (Cummings, 1976). A dad may believe he did not protect his family from the disability, and he may feel that many of the decisions the family must make are beyond his authority. In talking to other fathers about his son's schooling and the frustrations he regularly faces, a dad blurted, "You hit the Red Sea, and it doesn't part for you." He wanted to know how to make a difference in his child's life and how to gain a measure of control.

Anger and frustration are common denominators among men who have children with special needs. They may be angry that they don't know more about how to help and enraged that they cannot protect their families from the seemingly overwhelming problems that surface time and time again. Fathers may be frustrated that service delivery usually takes place when they are working, and that they too often become afterthoughts when it comes to the care of their children.

> *After we found out our first born was permanently brain damaged and severely/profoundly retarded I was devastated. . . . All I had on my mind was to fix blame on someone and pretend that it was all just a dream. In fact, the adjustments that I had to make were not easy or without some fierce stubbornness on my part.*
>
> *— Kenneth Braker*

Yet, also clear is the strength — some would call it courage — and the perseverance "to do what needs to be done," a remark these fathers commonly make when asked how they deal with the stresses in their lives. "What other choices do I have? I love my kids, and I love my wife. I can feel sorry for myself, or I

can get on with it and do what needs to be done." These pragmatic fathers view problems as challenges to overcome. Many fathers are not afraid to push limits and to be assertive if they need to be to open doors for their children.

Fathers of children with special needs routinely feel isolated. Contributing to this isolation is the difficulty fathers often have in accepting and understanding the reality of their children's conditions — both in the severity of the challenges and in the physical and emotional manifestations of the problems. Fathers are sometimes embarrassed and sensitive about their children's disabilities and physical appearance and about the effect their children have on family social status and image (Price-Bonham & Addison, 1978). As one father said, "My kid still isn't toilet trained at age six; why would I share that with my peers at work?" Fathers need information and other support on how they can talk about their children with relatives, coworkers, and strangers who may stare or make inappropriate remarks or comparisons.

Kids often stare at her and ask what's wrong with her. I don't mind, because I can tell them how being different makes her special. But, when she's older will she have any friends? Will other kids' curiosity turn into taunting? It really hits me when we're at the playground that Laura will never be normal. All the other kids are running and climbing and she needs my help. The oddity is that she has a great time, while I get depressed.

— Paul Malinowski

Fathers typically perceive that social supports from family, coworkers, neighbors, and community groups are limited (Ferrari, 1986). Often believing they must be "strong" at all costs, many men limit their potential for expressing concerns and fears and for finding strength through sharing with each other. A man may have difficulty getting in touch with the feelings swirling inside him, and his self-sufficiency often makes asking for help a formidable task. Work potentially becomes an escape and, too often, a means for dulling the pain.

Programs serving children with special needs have produced positive results by directly focusing on providing opportunities for fathers to increase their involvement. Among these results

> ***If we could only learn to more readily share the things that are stored up deep within; then we could possibly avoid the tragedy of stumbling over our own hurt and get on with the task of helping those who need us.***
>
> ***— Kenneth Braker***

are reduced stress and sadness, diminished depression and fatigue, improved self-esteem, more equal sharing of family responsibilities, and an enhanced family support system (Markowitz, 1984; Vadasy, Meyer, Fewell, & Greenberg, 1985).

Fundamental to a man whose child has special needs is his ability to reconcile conflicting conceptions of his role and to discover how to redefine himself as a father (Duvall, 1962). "It's as if the whole world crumbled before my feet, and I wondered where I would begin." New values slowly emerge; a new model of fatherhood develops. Speaking about his daughter, a Midwest father comments:

> It is often easy to withdraw as a parent of a disabled child. Forcing myself to take Laura to museums, stores, and even the dreaded playground has helped make me a better parent by giving me the confidence I need. . . . I feel proud of her and even proud of myself — that I'm a damn good father. The irony is, I probably wouldn't have been if I didn't have a special needs child.

Because most medical, therapeutic, and support services are provided during the day, a father's work schedule may limit his firsthand knowledge about his child's disability, thus creating the potential for a continuing information gap between mother and father. As a child matures and enters into early intervention programs, fathers will "characteristically have fewer opportunities to do something directly helpful for their handicapped child, something which provides concrete evidence of their loving, caring, and benevolent concern" (Cummings, 1976, p. 253).

Fathers who are fully engaged with their children are happier with themselves, show fewer signs of physical illness, and have spouses who are more satisfied with their marriages. Families with involved fathers also have children who better adapt to life's stresses (Pruett, 1989).

There is increasing evidence that the father sets the tone for a family's attitude towards a child with special needs (Frey, et al., 1989; Peck & Stephens, 1960; Price-Bonham & Addison, 1978). Frey and colleagues (1989) note:

> The association between the father's view of the child at Year 1 and the mother's view at Year 3 suggests that fathers' perceptions may be a potent influence on mothers. . . . The mothers whose spouses had a more positive view of the child became more positive themselves. (p. 52)

In assessing the needs for fathers' full participation in the lives of their children with special needs, Gallagher (1981) found that:

> Across all groups there was general agreement that there should be more father involvement with the handicapped child. The fact that this does not happen or has not happened is an area in need of investigation, but there is no doubt that it should happen. (p. 12)

The inescapable conclusion of the above research must be that fathers can regain control of their lives through coming to terms with their grief, finding emotional support, learning appropriate father-child interaction patterns, and becoming active participants in the decisions affecting their children's lives.

What can you say about a six-year-old, mentally retarded boy who smiles the first thing on getting up in the morning? What do you say about a boy who thinks getting hugs is better than getting Christmas presents? I sometimes think my other kids should follow his example. Perhaps we all should.

— Werner Wikander

Photo: Gary Sweet

Gary Sweet with his son Jacob

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A New Paradigm for Professionals

Professionals are a difficult lot to deal with. They have some specialized training, so they think they must have the answers. At least they seem to think that because we, as fathers, have not had the specialized training, we could not possibly have anything meaningful to say about our child's condition.

— The father of a child with cerebral palsy

Photo: Gary Sweet

Hameed Quraishi with his daughter, Sabra

Family-centered service delivery demands a full range of options for family involvement (Johnson, McGonigel, & Kaufmann, 1989; Shelton, Jeppson, & Johnson, 1987). The choices families and individual family members make from among these options will depend on family and individual values, beliefs, circumstances, and priorities as mediated by a family's culture and community. Unfortunately, for families whose children have special needs, options for involvement are too often limited to just one person, the mother. When the father or other male family members try to be involved, they are frequently ignored or neglected because their choice to be involved flies in the face of a long-held belief that many fathers have little or no desire to be engaged, vital participants in their children's lives.

Professionals can change this belief by promoting a new paradigm of service delivery, a paradigm that begins with recognizing the vital importance of paternal involvement in a child's life. Such an understanding starts with personal attitudes and perceptions. If little is expected of fathers, little may be delivered. The expectation that fathers want to participate in the care and treatment of their children must be a given.

Much has been written about male "deficits" in parenting. Parental characteristics such as sensitivity and nurturance are often identified as areas in which fathers are limited (Betterman, 1984). Studies have shown such assumptions to be untrue or misleading. Fathers, given opportunities, are nurturing caretakers in their parent-child interactions. As a means of ameliorating such negative perceptions, Palm (1988) suggests reframing male strengths to focus on areas such as playfulness, leadership, adventure, independence, and responsibility.

> ***Many professionals don't want to give parents false expectations of what their children might be able to do in the future, so they offer the parents little or no hope at all for their kids. What these professionals don't seem to realize is that parents have hopes for their children regardless of what professionals say — and many times the parents have been a better judge of what their child will do. Professionals seem to have too much regard for their own training, and too little respect for parents.***
>
> ***— A Father***

Men parent differently than women — not better, not worse, but differently. "Fathers don't mother, they father" (Pruett, 1989). Whether this difference is seen as an inherent male trait or as a product of male socialization in our culture, professionals are likely to see many men who feel most comfortable bringing a pragmatic approach and problem-solving expertise to personal, family, and societal concerns. Professionals can help fathers find ways to use the strengths inherent in this approach to parenting, whether in playing with and teaching their children one-to-one, building adaptive devices, making videotapes, developing systems of father-to-father support, or advocating for legislative change.

Never having been taught, men often do not know how to help their children with special needs. Few role models or programs exist to help them. Many programs effectively exclude fathers by the way in which they conceptualize and deliver services. Professionals must scrutinize existing programs — from policy to implementation — for potential roadblocks that limit or prevent male involvement. They must consider whether training materials reflect men's integral role in the family system and on their children's care team. Are men visible in agency, hospital, and school videotapes; in marketing brochures; and in parent

newsletters? Is technical, specialized information (i.e., physical/occupational therapy) available on videotape so that it can be taken home and shared with a dad?

When fathers are actively engaged in their children's daily activities, the majority of service delivery professionals they encounter will be women. While not inherently a problem, this reality does present some unique concerns. Henderson (1989) notes that male-female issues have either not been addressed or have been given only minimal attention. Foremost is the ability of men and women to develop ways to communicate effectively without personal issues cluttering the landscape.

We all bring personal agendas to our work and to our interactions with others. We bring our own fathers — and their strengths and weaknesses — to the work site: "How we feel about . . . male or female clients starts with our personal experiences and expectations" (Henderson, 1989). Staff training focusing on intimacy, sexuality, and working positively with men can help create positive environments for working with fathers. Discussions about setting limits; handling anger, aggressiveness, and confrontation; working through personal fears; and effectively engaging men while overcoming male stereotypes can add understanding and clarity to male-female interactions. Creating a supportive environment "has to be a shared commitment, with each sex drawing on their own strengths and the strengths of the other" (Henderson, 1989).

I needed a new windmill to attack. My children's future seemed to be that windmill. So, I went to parent training, and my self confidence has slowly started to grow. I was recently told something that helps me understand myself. Someone said, "Billy doesn't go anywhere that he doesn't leave an impression; some good, some bad, but he does leave one."

— Billy Rogerson

Fathers need recognition as experts in the nurturing of their children. Recognizing the importance of extended family, community, and culture is equally necessary. Only then can family-centered services become a reality. The results of such recognition are far reaching. Knowing that families are interconnected helps professionals understand that, although the child is the person with Down syndrome or

cystic fibrosis, all family members are grappling with the impact of the special needs on the joys, stresses, anxieties, hopes, and dreams shared by all families and all communities.

Failure to involve all family members in service delivery is akin to attempting car repair with a few engine parts missing. With some good fortune, the car might ultimately sputter down the road, but never in the smooth, coordinated manner it was meant to run. Ultimately, the car either will function very inefficiently or will break down altogether. So too with families. Obstacles must be removed so that families can use their inherent strengths and resilience to manage the situations at hand. Family life demands input and energy from all family members, including all of those persons an individual family defines as part of the family system, both "given" and "chosen" family.

For parents and professionals, the choices are clear. Pruett (1989) asks, "How far are we willing to go out of our way to make it more than nice, but to make it important" for fathers to be more directly involved with their children? This new paradigm of involved fatherhood puts dad back in the family, views men as nurturing parents, and seeks opportunities for fathers' involvement in all aspects of their children's lives.

Photo: Mary Wilson

Bill Wilson and his son, Willie

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Strategies for Effective Service Delivery

Transporting my son to a special hospital unit, arranging care for the other children, notifying relatives, clearing the calendar for the next few days — immediate involvement. . . . Late that evening, when things had calmed, when thoughts began to flow free, I could feel good about the things I had done. I felt that my actions were important to my son's survival.

— Dale Loftis

Photo: James May

Eustaquio Nabong with his children, Effie, Elaine, Eugene, Ethel, Erhiza, and Errold

The new paradigm for fathers' involvement discussed in Chapter Three will become a reality through the development and implementation of effective service delivery models that speak to the special needs of fathers. These models must be built into the infrastructure of existing programs, agencies, clinics, hospitals, and schools. Effective father supports are not periodic attempts to increase male involvement in service programs. Rather, they are thoughtfully planned, well-organized initiatives to effect change in service delivery patterns, consistent with the needs of the fathers themselves.

Engaging Fathers and Encouraging Male Participation

Forces are set in place the moment a family whose child has special needs first contacts a professional or service delivery system.

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Programs and professionals should make every effort to have fathers participate in these first contacts, consistent, of course, with the wishes of individual fathers. The longer a man stays away from services, the harder it will be to engage him in the future. By not reaching out to men, programs and professionals are unwittingly setting in place assumptions that mothers are expected to be the primary caregivers and that fathers are unable or unwilling to be a member of the care team.

To welcome fathers' participation, programs and professionals should ask about the men in a child's life, be they fathers, grandfathers, uncles, friends, or neighbors. Men who are involved in the child's life should be invited to become a member of the care team. Welcoming and encouraging father participation takes a conscious shift in practice for many professionals, but there are daily opportunities to send a message that fathers and other significant males are uniquely valuable and necessary in the lives of children:

- Calls to a child's home can be made at times when fathers as well as mothers are likely to be home and available to talk.
- Information contained in assessment records and care plans should be written in a way that is respectful of both parents.
- If care plans, permission to treat or participate in services, or other plans or forms are signed when the father is not present, send copies home specifically for him.
- When a father is not living at home, information and other materials should be sent to the father's home as well as to the home where the child lives, if the mother or legal guardian gives permission for such sharing of information. If parents have joint custody of the child, information can be shared without such permission, but it is wise to discuss this issue first with the parent bringing the child for services.

FLEXIBLE SCHEDULING

It is imperative that programs be responsive to a father's work schedule. Appointments should be made with enough lead time to accommodate the daily calendars of both fathers and mothers. Consider having early morning, late afternoon, or Saturday program or care planning meetings. Offerings in the evening or on Saturday mornings are an attraction for many men, particularly if child care is provided so that both parents can attend. Such innovative scheduling requires that agencies and programs negotiate work contracts with staff that include flex-time and other options that will allow them to work nontraditional schedules to meet family needs.

PROGRAMS OF SUPPORT

Effective support for fathers sends a message that it is normal and expected for men to ask for and get help and support. Father support should be as personal and "hands on" as possible. A myriad of options exist. The following are just a few examples:

- Organize special events specifically oriented toward fathers and their unique strengths and needs. For example, sponsor a "Pops 'n Tots" program for fun and education.
- Convene a panel of fathers to present their perspectives on what it is like to be the dad of a child with special needs. Have fathers organize and chair such panels and other meetings as well.
- Offer parenting classes for fathers, led by fathers and male professionals. Make them low key and nonthreatening, with an emphasis on enjoyable father-child activities, informal discussion, and information sharing about child behavior and development. One such successful model calls its program "Super Saturdays" (Palm, 1988). Build these programs from the "inside out," developing curriculum to meet the stated interests, priorities, and concerns of the men involved.

- Include, in program newsletters and other materials, a column or articles specifically aimed at fathers and written by fathers and other men. Ask the men to use language that is active, engaging, and written at an easy to read level.
- Offer a father support group, run by fathers and assisted by male professionals. Such a program can operate in diverse ways beyond the traditional discussion and speaker format. This group, as with any support activity, should be tailored to the culturally mediated values and beliefs of the men involved.
- Encourage fathers to develop one-to-one peer helping relationships by pairing them according to similar personal concerns or comparable child factors, such as disability or age. Reach out to local parent-to-parent organizations for help in developing such peer support. Perhaps they will choose to start a father-to-father network.
- Set up social occasions for men to gather, converse, and exchange ideas, as well as for the promotion of father-child involvement. This not only relieves some of the isolation men feel, but also provides them with a nonthreatening environment in which to develop contacts for support.
- Sponsor family weekends and potluck suppers that expect and encourage the participation of both mothers and fathers, as well as that of other family members.

The above examples are just a smattering of possibilities. A brainstorming session of staff and fathers will yield many more creative ideas and options for supporting dads. In their study of fathers of children with special needs, Linder and Chitwood (1984) reminded professionals to offer a range of alternatives that are consistent with the emotional and educational readiness of the men in the programs.

Professionals should make no assumptions about what fathers will find supportive. The only way to know is to ask. Similarly,

professionals should not assume that what some fathers find supportive, all fathers will find supportive. Not only do individual men vary greatly in their preferences for support, but significant differences also exist among groups of men according to culture, ethnicity, and socioeconomic background. Program staff must be proactive, reaching out to the communities their agency or clinic serves. It is not enough just to ask the men who show up — much more of value might be learned by discovering the preferences and priorities of the men who do not come to the program. Are there aspects of the program that implicitly exclude or devalue men from particular cultures or communities? Roberts (1990) provided many useful suggestions for ensuring that programs and services are rooted in the communities and cultures of which they are a part.

READILY AVAILABLE AND EFFECTIVE RESOURCES

Fathers need opportunities to recognize means for making positive contributions in their children's lives. A resource room for fathers can be of particular benefit if it contains accurate, easily accessible information about topics that often are of special concern to fathers, including legal rights; government medical benefits and private insurance; trusts, wills, and guardianships; educational advocacy; and vocational and independent living options. Also quite valuable are resources focusing on the sharing of personal experiences by other parents, especially fathers, on coping with common concerns and emotions.

A library of videotapes regarding medical and therapeutic procedures also can be an effective vehicle for fathers to learn how to help their children. In the privacy of their own homes and on their own time schedules, fathers can use these tapes to close the gap between the mothers' and their own knowledge about such topics as medical procedures, care techniques, therapeutic interventions, language development, or behavior management techniques or models. In families in which reading skills are limited, videotapes allow easy access to vital information.

Since many families do not have videotape players, programs can provide a comfortable space for viewing tapes in a fathers' resource room. If space constraints do not permit establishing a resource room for fathers, a bulletin board for dads can be set up in common areas such as the lounge in the neonatal intensive care unit (NICU), hospital, clinic, or school.

DEVELOPING CULTURALLY COMPETENT PROGRAMS

Culturally competent programs are "derived from the cultures they seek to serve" (Adams, 1990, p. 4). Cultural competence can be defined as:

> a set of congruent behaviors, attitudes and policies that come together in a system, agency or professional and enable that system, agency or professional to work effectively in cross-cultural situations. . . . A culturally competent system of care acknowledges and incorporates — at all levels — the importance of culture, the assessment of cross cultural relations, vigilance toward the dynamics that result from cultural differences, the expansion of cultural knowledge and the adaptation of services to meet culturally unique needs. (Cross, 1988, p. 1)

Becoming culturally competent is a challenge that must be met by all programs and professionals wishing to develop or expand support services for fathers. Without such careful attention to the cultural context of the planned services, a successful program of support is unlikely to be achieved.

In defining the hallmarks of culturally defined programs, Adams (1990) noted:

> Emphasis is placed upon maintaining and/or improving the self-esteem, cultural identification, and goal setting ability of each family, with special attention to assisting the family to achieve and maintain self-sufficiency with the context of the larger family. (p. 5)

Understanding the role of the father in the family hierarchy is a crucial component in such a "cultural fit."

Thus, in any program of father support, the espoused values, program curriculum, and program activities must parallel the values of the families being served. For example, in many cultures, family privacy is a primary value. Fathers from these cultures may not feel comfortable discussing personal concerns with other men they do not know. Thus, a group program may not be an effective or appropriate support for these fathers. Natural systems of support (i.e., extended family, peer assistance, the church) may be a more suitable means of sharing and gaining information.

Cross (1987) described a continuum of cultural competence that ranges from cultural destructiveness at the low end, to cultural blindness as a middle point, to advanced cultural competence at the high end. This discussion is a valuable resource for programs and professionals who are endeavoring to support fathers in a way that is consistent with one of the key elements of family-centered care, "honoring the racial, ethnic, cultural, and socioeconomic diversity of families" (National Center for Family-Centered Care, 1990).

Few fathers' support groups will be made up of men from only one culture. More likely, such groups will be mixed racially, ethnically, and religiously. In addition, the men involved in any particular group, even if ostensibly from the same cultural background, are likely to represent a continuum from "traditional" to "assimilated" in terms of their cultural identity.

This identity is not easy to read. A professional cannot look at a man and know to what extent he subscribes to the tenets of traditional culture, and cultures themselves are continually changing as they adapt to new realities. Therefore, the best way for a professional to be culturally competent in a mixed or unfamiliar group is to be honest about one's own lack of knowledge of the backgrounds, beliefs, and values represented by the fathers and to invite their open communication on these issues. This approach offers immediate value and empowerment to the fathers; it implies, "I acknowledge you as an individual, different from myself, and I value you enough that I want you to teach me about who you are."

His smile is a beam of light. Nothing is more rewarding for a dad than that welcome look when I come home at the end of the day, of complete and unconditional love, and one hug makes the day's troubles melt away.

— Dana Reed

Photo: James May

Mark Niklason with his sons, Josh and Kevin

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Support Programs for Fathers

Good fathering flows from the realization that being a father is important, vital, demanding, rewarding, and risky. . . . Telling your story of what it is like to be your father's son and your child's father to another father and another, and listening to their stories in return is ultimately the only school for fathering.

(Streiker, 1989, p. 55)

Photo: James May

Members of the Fathers' Program at Merrywood School, Bellevue, Washington

Increasing numbers of men who have children with special needs have learned the value of sharing their lives with other fathers. By reaching out to someone who truly understands, an uncommon camaraderie develops, filled with earthy humor and a belief that fathers make an immense difference in their families' lives. These men are constructing a new vision of what families are all about.

Why father support programs? Might it not be preferable for fathers and mothers to come together? Many couples do attend support programs together, and both benefit from the contacts, the understanding, and the information. Yet, many men remark that when they attend such programs, they are almost always in the minority and that they often feel detached and out of place. Some of the topics covered are not of primary interest to them, and the discussion, which frequently involves intense feelings, makes some men uncomfortable. Particularly when their wives are present, men may respond in a conditioned manner rather

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> ***Dads need to talk with other dads, and the Father's Group provides that forum for discussion. Each group can work out its own style, but it is important for the fathers to talk together. Men tend not to get together in support groups. That is hard for some men to overcome, but with encouragement and support for their group, men are much more likely to get together and talk over problems of raising their special children.***
>
> ***— A Father***

than disclose their true feelings. A fathers' program gives many men confidence in their parenting skills and a chance to develop a relationship with other men in similar circumstances.

Programs for fathers are not designed to compete with other programs, nor are they a "must do" for all men. Instead, they are an avenue for men to meet other men who have common concerns, a time to gain expertise in the care of children with special needs, and a place to be involved in developmentally appropriate father-child activities in an atmosphere that quietly illuminates how irreplaceable fathers are in the lives of their children and their families. As one man commented simply, "Dads need to talk with other dads." Another added, "The fathers' support group has allowed me to meet many other caring dads with needs and goals like mine, in a low-key and positive environment. It is my time away with the guys."

The design of effective support programs for fathers needs to be consistent with the principles of family-centered service delivery. Fundamental is the core belief that fathers are able, effective parents — competent and capable in coping with the challenges they face. Programs should be built from the inside out, developed according to the strengths, needs, priorities, and desires of the fathers being served. Participants are asked, "What will make this program valuable for you?" Inherent is a flexibility and readiness to change if the needs change. Thus, attention is paid to both product and process, the what and the how.

A fathers' support program values listening as the highest form of respect. Judgments are limited, and acceptance is the norm. Facilitators know the difference between "listening with" and "talking at." A foundation for trust is built by assuming that all

men involved can work together in a spirit of cooperation. The men will gain confidence in their ability to care for their children, for each other, and perhaps most importantly, for themselves.

LEADERSHIP

Inherent in the philosophy of a fathers' support program is the rule that the program is run by fathers for other fathers, assisted by male professionals when desired. The crucial people are the fathers themselves. One or two dads should be identified as primary facilitators; their fatherhood of a child with special needs is the basis for their credibility. Facilitators should have an emotional maturity that allows them to model appropriate self-disclosure and to subordinate their personal needs to those of the other men in the group. Facilitators should be well organized, active listeners who are always willing to reach out to other fathers. Enthusiasm is essential. Effective fathers' support programs almost always have a "core" of four or five men who provide leadership, participate actively, and are willing to pitch in and do what it takes to make the program successful.

> ***The group allows me to air problems, accomplishments, fears and needs. I can talk, or I can just listen . . . that's nice. I think every father of a special needs kid should attend a father's group for nothing else than to see that maybe his situation is not as bad as he originally thought. I know that may sound a little cryptic, but I think it helps to put one's situation in perspective.***
>
> ***— Curtis Young***

A male professional assisting in a fathers' support program should have a background in child and family development. It is also helpful if he has experience working with families of children with special needs. Critical characteristics of this professional include:

- respect for and working knowledge of the cultures that make up the communities of which the fathers are a part;

- possession of an effective resource base (materials, speakers);
- ability to generate a solid base of referrals (counselors, programs);
- organizational ability (for recruitment, finances, scheduling); and
- understanding of group dynamics and group facilitation skills.

Beyond these characteristics, vital qualities for the professional are compassion, sensitivity, and unbridled enthusiasm for the fathers and for the families they represent.

MEMBERSHIP

Successful programs recognize that fathers have common concerns that unite them, and most choose not to focus on a specific disability or child age group. The majority of men who attend fathers' support groups have children between birth and ten years of age. Fathers' support programs should be open to *all* men who have children with special needs, including single fathers, custodial and noncustodial dads, and other men who fulfill the role of "father" in the lives of children with special needs.

STRUCTURE

The majority of fathers' support programs meet on Saturday mornings, a time when many dads are not working. This timing also allows the fathers to bring their children for activities. Typical meeting length is two to three hours. Almost all programs include some variation of the following activities:

- social time with other men;
- father-child activity;
- sharing and discussion; and
- educational component (speaker, video, exercise).

Men in fathers' support programs often come together through social occasions. These are relaxed, safe times to meet other fathers of children with special needs. Successful outings include picnics and barbecues; campouts; and trips to a zoo, aquarium, or children's museum. A fathers' program also might sponsor a Very Special Arts event, where artists engage families in hands-on activities. These are excellent opportunities to recruit new dads to join the program.

The father-child activity is an enjoyable time when dads can learn and practice appropriate parenting and child communication skills. The fathers also learn by observing other men interacting with their children.

The critical program element is the sharing and discussion, a time men openly talk about their concerns and frustrations, their joys and successes. It is also a place for elation, a moment to brag about their children's accomplishments — accomplishments that may seem small to some people, but seem ever so large to other fathers of children with special needs. This sharing is the foundation for trust and understanding among the men in the group. The hard-to-ask question or candid observation finds acceptance in this arena.

The educational component is a relaxed, informal opportunity to learn pertinent information about selected subjects. Typical topics include medical concerns; program or care plans; trusts, wills, and guardianships; and educational advocacy. Issues covered evolve from the discussions that take place during the sharing part of the meeting. Many groups welcome mothers to this educational component. Child care is often made available during the sharing and learning components of the program.

Matt is a burden at times and our lives have changed in order to accommodate his needs. It's not always fun, but you learn to adapt to the situation and make the best of it. . . . Most of the time, Matt is fun to be with, and I think this is a special thing with any child.

— Werner Wikander

The structure of support programs for fathers varies widely. While many meet twice a month, others meet once every three or four weeks. Some programs chose to meet on weeknights, thereby limit-

ing the father-child activities. While some programs have all of the above components, some choose only one or two components. Some alternate one segment each time — discussion only, activity only, speaker only. The structure of a particular program is based on the wishes of the fathers who participate.

SPONSORSHIP

Fathers' programs are sponsored by a variety of institutions, including early intervention agencies, public health clinics, hospitals, schools, disability-based organizations (i.e., Down syndrome, Muscular Dystrophy, Spina Bifida), parent advocacy groups, and university affiliated centers. Often two or three organizations cosponsor a group to build a broad base for recruiting fathers. Cosponsorship also allows costs to be shared.

RECRUITMENT AND MARKETING

Sponsoring organizations take responsibility for advertising the program to the families they serve. A brochure or flyer explaining the nature of the program and listing the meeting calendar is helpful. The most effective recruiters are the fathers themselves. A phone call followed by a personal invitation to attend yields the best results. Most groups either delegate men to call fathers before each meeting or send a letter home detailing the expected activity, speaker, place, and time. Letting pediatricians, hospitals, early intervention programs, and other organizations know about the group has proven successful, as have articles in local newspapers, appearances on television and radio, and public service announcements.

LOGISTICS

To make a support program for fathers as inclusive as possible, there should be no charge for fathers to attend. Some programs charge a nominal fee for child care. Most programs have fund

raisers such as pancake breakfasts or rummage sales, or gain financial support through small grants from community organizations such as Kiwanis or Rotary.

Many groups choose to gather away from the hospital or institution to provide a nonclinical meeting place that is cheerful and upbeat. Being met by another father and given a name tag and a cup of coffee eases early moments of anxiety for many fathers. Sitting in a circle so all fathers can be seen creates a relaxed, open atmosphere. To enhance personal investment, the men need to take responsibility for elements of the program, whether that be recruiting, telephoning, coffee making, or cleaning up.

GROUP NORMS

Support programs for fathers have few rules. Attendance is voluntary, as is bringing one's child. Respect for differences of opinion and belief is vital to the group's success, as is confidentiality. The men discuss what these concepts mean to each other, particularly regarding what is shared outside of meeting times. All programs have found it important to help the men learn how to actively listen to one another. Leaders model being fully supportive of all participants to help the fathers learn how to support one another.

EVALUATION

Most programs for fathers have a relatively small number of participants. It is a mistake to define success by the number of men attending the program. If the men attending, whether 3 or 13, find the program beneficial and choose to return, then a successful program is in place. Consistent efforts to encourage written and verbal feedback help focus on what the men really want from the program, as do frequent needs assessments for topics, speakers, activities, and subjects worthy of discussion.

RESULTS

A fathers' support program is a powerful vehicle for strengthening male support and parenting skills. Almost always there is pointed discussion and hearty laughter. To share a child's first steps, the success of a happy mealtime with a child who has feeding problems, the relief of making it through a serious childhood surgery, or the joy of taking a son or daughter swimming — these are the moments that speak to a new kind of fathering. While the men involved might seem very different, in truth they are very much alike. In looking back at his years of group involvement, Patrick Giorgetti reflected, "The fathers' program was something that made me able to share and feel important in the raising of my child. The program was like a family to me, and those friendships I've made will be there for a lifetime. Every one of those fathers has a special place in our family's heart."

A funny thing happened to me after Sarah's birth. I used to be very good at drifting through life and basically doing as I pleased. Sarah, and what she meant to me, changed that way of life in me forever. Today, 7-1/2 years later, I have become a "giving" person who finds a real need to reach out and help. . . . At first, I did it because I needed to get through the grief, and becoming a volunteer seemed to help me cope. I continue today because the needs are still great and our society just doesn't care enough to help fill all the gaps.

— Paul Egly

William Sherertz with his daughter, Rebecca

A Vision for the Future

HELP WANTED:
Dads. Fathers. Grandfathers. Stepfathers. Stepgrandfathers. Godfathers. Job description: remains to be seen. Responsibilities: many and varied. Salary: You pay for the privilege. Fringe benefits: whatever you can get. Special bonus package: a sense of permanence, rootedness, self-esteem, and belonging; delight in hugging and being hugged; memories of smiling and being smiled at, playing catch, pushing a swing, building a doll house; pride, being needed, and knowing that you made a difference. (Streiker, 1989, p. 220)

Photo: James May

Jeff Raefield with his son, Travis

Stereotypes regarding fathers die slowly: "There is an underlying assumption particularly difficult to outgrow; mom is necessary and fundamental; dad is expendable, though very nice to have around" (Wolfe, 1989, p. 3). A new model of fathering is emerging, tempered by lessons learned from children with special needs:

> He taught me to listen, to ponder, and perhaps to touch, in the best way I can, those around me because these qualities are the most human we have. (Biondello, 1988, p. 43)

These are "lessons I should have learned earlier in life," noted one dad. For many fathers the reward is in discovering an ability to be remarkably supportive of their families, their children, and themselves. Father as caregiver and nurturer emerges.

Samuel Meisels (1985) wrote:

> Evidence exists to support the view that the primary intervention target should not be the child, but the child within the context of the family. . . . The family and its sociocultural and economic context is the crucible in which forces for good and ill are transformed into developmental patterns for high risk and handicapped children in the first years of life. The evidence from a whole generation of research demonstrates that the quality of parents' behavior as caregivers and as teachers makes a difference in the development of infants and young children. (p. 2)

This monograph has suggested many areas for fathers' support. Fathers of children with special needs demand recognition and understanding. Beyond that, they need programs that actively promote father-child involvement. Such programs engender positive change for the entire family; the family mobile is appropriately rebalanced. Randi Wolf (1989) eloquently declared:

> Children need and deserve the love and attention of *both* parents. Let's work together so that every parent is fully respected and every child has the opportunity to establish close bonds with both men and women right from the start. . . . There is nothing more important than our families and nothing more critical to the long-range future of our species than raising our children well. As there is also nothing more difficult, it makes sense to muster all of the forces available. In this spirit, let's begin to recognize and welcome fathers as full and equal partners in this task. (p. 3)

HELP WANTED: Professionals — physicians, early intervention practitioners, nurses, social workers, educators, physical and occupational therapists, psychologists, mental health counselors, day care personnel, language specialists — all those working with families of children with special needs. Job description: design and implement family-centered, culturally competent models of service delivery that encourage increased

involvement of fathers in the lives of their children with special needs. Rewards: reduced isolation for untold numbers of men *and* women, redistribution of child-rearing tasks, increased bonding of dads with their children. Direct benefits: enhanced job satisfaction, delight in watching fathers gain heightened control of their lives, appreciation from many. When needed: now. In fact, long overdue!

We don't have to pretend to be so strong. We can admit that life does hurt sometimes, that my child does have some problems, that I have lost that perfect child of my dreams. Having admitted this, I am now free. Free to meet the challenges of tomorrow. Free to be excited about even the smallest progress. Free to make those adjustments necessary to give my son the best family I can give, to be the best Dad I can be. And I will be there for him because he is my son!

— Dale Loftis

Photo: James May

Chris King with his son, Andrew

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Resources for Parents and Professionals

The following books, other materials, and organizations are highly recommended as resources for understanding the special concerns of fathers and their families. Many of these resources examine the changing roles of fathers during the past decade and the implication of such changes for improved service delivery. The resource list is separated into specific categories for ease of use.

Books on Fathers: Raising a Child With Special Needs

Greenfeld, J. (1970). *A child called Noah*. New York: Pocket Books.

McGuire, J., & Beail, N. (Eds.). (1982). *Fathers: Psychological perspectives*. London: Junction Books.

Meyer, D. J., Vadasy, P. F., Fewell, R. R., & Schell, G. C. (1985). *A handbook for the Fathers' Program*. Seattle: University of Washington Press.

Books on Fathers: Their Changing Roles

Baumli, F. (Ed.). (1985). *Men freeing men — Exploding the myth of the traditional male*. Jersey City, NJ: New Atlantis Press.

Bell, D. H. (1982). *Being a man: The paradox of masculinity*. Lexington, MA: Lewis Publishing Co.

Bly, R. (1990). *Iron John: A book about men*, New York: Addison-Wesley Publishing Co., Inc.

Clary, M. (1982). *Daddy's home*. New York: Seaview Books.

Colman, A., & Colman, J. (1981). *Earth father/Sky father*. Englewood Cliffs, NJ: Prentice-Hall.

Farrell, W. (1986). *Why men are the way they are.* New York: McGraw-Hill.

Goldberg, H. (1976). *The hazards of being male: Surviving the myth of masculine privilege.* New York: Signet.

Goldberg, H. (1979). *The new male.* New York: Morrow.

Kort, C., & Friedland, R. (1986). *The fathers' book: Shared experiences.* Boston: G.K. Hall & Company.

Lamb, M. E. (1983). *Fatherhood and family policy.* Hilldale, NJ: Lawrence Erlbaum Associates.

Levine, J. (1976). *Who will raise the children: New options for fathers (and mothers).* New York: J.B. Lippincott Co.

Parke, R. D. (1981). *Fathers.* Cambridge, MA: Harvard University Press.

Pruett, K. (1987). *The nurturing father — Journey toward the complete man.* New York: Warner Books.

Robinson, B., & Barret, R. (1986). *Fatherhood.* New York: Guilford Press.

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Russell, G. (1987). *The changing role of fathers.* St. Lucia, Australia: University of Queensland Press.

Sayers, R. (1983). *Fathering: It's not the same.* Larkspur, CA: The Nurtury Family School.

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Stewart, D. L. (1980). *Fathers are people too.* New York: Bobbs-Merrill.

Yablonski, L. (1982). *Fathers and sons.* New York: Simon & Schuster.

BOOKS ON FATHERS: PREGNANCY, BIRTH, INFANCY, AND CHILDHOOD

Barkin, R. M. (1988). *The fathers's guide: Raising a healthy child.* Golden, CO: Fulcrum, Inc.

Bittman, S., & Rosenberg, A. (1978). *Expectant fathers.* New York: Hawthorne Books.

Fields, S. (1983). *Like father, like daughter.* Boston, Little Brown & Company.

Green, M. (1976). *Fathering.* New York: McGraw-Hill.

Greenberg, M. (1985). *The birth of a father.* New York: Avon Books.

Greene, B. (1985). *Good morning Merry Sunshine: A father's personal journal of his child's first year.* New York: Penguin.

Gresh, S. (1982). *Becoming a father.* New York: Bantam.

Heinowitz, J. (1982). *Pregnant fathers: How fathers can enjoy and share the experiences of pregnancy and childbirth.* Englewood Cliffs, NJ: Prentice Hall.

Hobbs, N., Dokecki, P. R., Hoover-Dempsey, K. V., Moroney, R. M., Shayne, M. W., & Weeks, K. H. (1984). *Strengthening families: Strategies for improved child care and parent education.* San Francisco: Jossey-Bass.

Lamb, M. (1981). *The role of the father in child development.* New York: John Wiley & Sons.

Lapinsky, S., & Hinds, M. D. (1982). *In a family way: A husband and wife's diary of pregnancy, birth, and the first year of parenthood.* Boston: Little Brown & Company.

Roth, E., & Reich, H. (1960). *Children and their fathers* (photographs). New York: Hill and Wang.

Russell, G. (1983). *A practical guide for fathers.* Melbourne, Australia: Sphere Books.

BOOKS ON FATHERS: FAMILY LAW AND DIVORCE

Galper, M. (1980). *Joint custody and co-parenting: Sharing your child equally.* Philadelphia: Running Press.

Ricci, I. (1980). *Mom's house, Dad's house.* New York: Macmillan Publishing Co.

Ware, C. (1982). *Sharing parenthood after divorce: An enlightened custody guide for mother, father and the kids.* New York: Viking Press.

BOOKS ON FATHERS: TEENAGE AND SINGLE FATHERS

Covington, J. (1982). *Confessions of a single father.* New York: Pilgrim Press.

Robinson, B., & Barret, R. (1988). *Teenage fathers.* Lexington, MA: Lexington Books.

Rosenthal, K., & Keshet, H. (1981). *Fathers without partners: A study of fathers and the family after marital separation.* Totowa, NJ: Rowman and Littlefield.

Sifford, D. (1982). *Father and son.* Philadelphia: Westminster Press.

BOOKS ON FAMILIES OF CHILDREN WITH SPECIAL NEEDS

Featherstone, H. (1980). *A difference in the family: Life with a disabled child.* New York: Basic Books.

Fewell, R. R., & Vadasy, P. F. (1986). *Families of handicapped children: Needs and supports across the lifespan.* Austin: Pro-Ed.

Gallagher, J. M., & Vietze, P. M. (Eds.). (1986). *Families of handicapped persons: Research, programs, and policy issues.* Baltimore: Paul H. Brookes.

Hobbs, N., & Perrin, J. M. (Eds.). (1985). *Issues in the care of children with chronic illness.* San Francisco: Jossey-Bass.

Meyer, D. J., & Vadasy, P. F. (1986). *Grandparent workshops: How to organize workshops for grandparents of children with handicaps.* Seattle: University of Washington Press.

Meyer, D. J., Vadasy, P. F., & Fewell, R. R. (1985). *Sibshops: A handbook for implementing workshops for siblings of children with special needs.* Seattle: University of Washington Press.

Meyer, D. J., Vadasy, P. F., Fewell, R. R., & Schell, G. C. (1985). *Living with a brother or sister with special needs: A book for sibs.* Seattle: University of Washington Press.

Murphy, A. T. (1981). *Special children, special parents.* Englewood Cliffs, NJ: Prentice-Hall.

Perske, R. (1981). *Hope for the families: New directions for parents of persons with retardation or other disabilities.* Nashville: Parthenon Press.

Powell, T. H., & Ogle, P. A. (1985). *Brothers and sisters: A special part of exceptional families.* Baltimore: Paul H. Brookes.

Schleifer, M., & Klein, S. (1987). *The disabled child and the family.* Baltimore: Paul H. Brookes.

Seligman, M. (1983). *The family with a handicapped child.* New York: Grune & Stratton.

Simons, R. (1987). *After the tears: Parents talk about raising a child with disabilities.* New York: Harcourt Brace & Jonvanovich.

Turk, D., & Kerns, R. D. (1985). *Health, illness and families: A life-span perspective.* New York: John Wiley & Sons.

Turnbull, A. P., & Turnbull, H. R. (1978). *Parents speak out: Views from the other side of the mirror.* Columbus, OH: Charles E. Merrill.

VIDEOTAPES ON FATHERS

Corcos, L. (Author). (1989). *The dad film* [Videotape]. Boston: Fanlight Productions.

May, J. (Producer). (1989). *Special kids, special dads: Fathers of children with disabilities* [Videotape]. Bellevue, WA: SEFAM Family Support Program, Merrywood School. Available from ACCH or Merrywood School, 16120 N.E. Eighth St., Bellevue, WA 98008.

Young Adult Institute. (1987). *Fathers* [Videotape]. New York: Author.

OTHER RESOURCES ON FATHERS

The Fatherhood Project. *Fatherhood U.S.A.* New York: Families and Work Project.

A guide to programs, services, and resources for and about fathers, including teen fathers. Other resources are available from The Fatherhood Project, c/o James Levine, Families and Work Project, 330 Seventh Ave., New York, NY 10001 (212) 465-2044.

Nurturing today — For self and family growth [Quarterly journal]. San Francisco: Nurturing Today.

(A bibliography of films and videos about fathering and other men's issues is available from *Nurturing Today*, Department FP, 187 Caselli Ave., San Francisco, CA 94114 (415) 861-0847.)

SEFAM Family Support Program, Merrywood School, Bellevue, WA.

The SEFAM Family Support Program is funded by the Maternal and Child Health Bureau, United States Department of Health and Human Services through a grant to the Association for the Care of Children's Health. SEFAM provides training and technical assistance on issues relating to fathers of children with special needs. Contact James May, SEFAM Family Support Program, Merrywood School, 16120 N.E. Eighth St., Bellevue, WA 98008 (206) 747-4004.

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About the Author

James E. May, M.A., M.Ed., is Director of the SEFAM Family Support Program, Merrywood School, Bellevue, Washington. SEFAM, a subcontractor to the National Center for Family-Centered Care at ACCH, provides training and curricula focused on fathers of children with special needs. Mr. May, an educator and mental health therapist with degrees in counseling and applied behavioral science, has worked with families and young people for more than 25 years. He is married and has a daughter. Children are the great joy of his life.

Photo: Gary Sweet

James May with his good friend, Josh